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## General practice palliative care: Patient and carer expectations, advance care plans and place of death-a systematic review

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## **ABSTRACT**

**Background:** With an increasing ageing population in most countries, the role of general practitioners (GPs) and general practice nurses (GPNs) in providing optimal end of life (EoL) care is increasingly important.

**Objective:** To explore: 1) patient and carer expectations of the role of GPs and GPNs at EoL; 2) GPs' and GPNs' contribution to advance care planning (ACP); and, 3) if primary care involvement allows people to die in the place of preference.

**Method:** Systematic literature review. Data sources: Papers from 2000 to 2017 were sought from Medline, Psychinfo, Embase, Joanna Briggs Institute and Cochrane databases.

**Results:** From 6209 journal articles, 51 papers were relevant. Patients and carers expect their GPs to be competent in all aspects of palliative care. They valued easy access to their GP, a multi-disciplinary approach to care and well-coordinated and informed care. They also wanted their care team to communicate openly, honestly and empathically, particularly as the patient deteriorated. ACP and the involvement of GPs were important factors which contributed to patients being cared for and dying in their preferred place. There was no reference to GPNs in any paper identified.

**Conclusions:** Patients and carers prefer a holistic approach to care. This review shows that GPs have an important role in ACP and that their involvement facilitates dying in the place of preference. Proactive identification of people approaching EoL is likely to improve all aspects of care, including planning and communicating about EoL. More work outlining the role of GPNs in EoLC is required.

## INTRODUCTION

Primary care is the foundation of care at the end of life (EoL) in most developed health systems. With the increasing ageing of the population, a paradigm shift is occurring in the provision of end of life care (EoLC), whereby the numbers of people approaching death will increase rapidly,<sup>1</sup> and the way EoLC is approached has changed significantly.<sup>2</sup> Whilst specialist palliative care (PC) services predominantly treat cancer patients, most people will die of non-malignant diseases, either specific organ failure, or multiple conditions.<sup>3</sup> The most common causes of death with a predictable EoL are heart failure, cerebrovascular disease, end-stage respiratory conditions,<sup>4</sup> multimorbidity, frailty and the dementias.<sup>5 6</sup> These people are much less likely to be offered specialist PC<sup>7 8</sup>; rather, their care is delivered by primary care and various medical specialists. Most spend the majority of the last year of life at home, either cared for by spouses of similar age, often with their own health problems, and/or by adult children with their own work and family.<sup>9 10</sup>

However, general practitioners and family physicians (henceforth termed GPs) may under-identify the need for EoLC in patients with non-malignant conditions.<sup>11</sup> Organising EoLC in these patients requires: identification of the risk of dying (and attendant escalation of palliative care needs); skilled management of multiple medical problems, minimising the risk of complications, organisation and sometimes coordination of appropriate multidisciplinary care; ensuring that the patient's wishes about their EoLC are known and respected, and that the needs of the carers are recognised and met. Any GP treating older people is involved in EoLC whether they recognise their involvement or not.

In Australia, about 70% of urban GPs reported providing palliative care.<sup>12</sup> Of those reporting they did not, more were younger, had been trained for a shorter time, female, part-time, not trained in Australia and were employees rather than practice principals. This mirrors the demographics of the younger GP workforce in Australia and almost certainly elsewhere. Participation in providing palliative care is higher in regional and rural areas, because the GP is the primary source of medical expertise.<sup>13-15</sup> While 72% of GPs in London indicated that palliative care is central to their role, 65% reported providing palliative care to their patients. Being from a larger practice, being trained for longer, and

receiving palliative care training and currently providing palliative care were independently associated with agreeing that palliative care was a core GP responsibility.<sup>16</sup>

The involvement of patients in health decision-making promotes satisfaction and compliance with care, improves outcomes for carers, and is increasingly recognised as a quality indicator.<sup>17</sup> GPs' role in EoLC will continue to evolve in response to the changing expectations of consumers. General practices have evolved to include a strong role for general practice nurses. (GPNs) There have been growing calls to keep GPs and GPNs engaged in EoLC and to build capacity in providing a palliative approach to care in the primary care setting.<sup>18</sup>

In 2002, GM published a systematic review of literature to 2000, documenting GPs' performance in undertaking palliative care.<sup>19</sup> Recognition of the critical role of primary care in providing EoLC has exploded since then, and a vast literature has ensued. An Australian initiative, the Primary Care Cancer Clinical Trials Collaborative group (PC4), undertook to update the 2002 systematic review. This current review explores: 1) patient and carer expectations of the role of primary care at EoL; 2) GPs' and GPNs' contribution to advance care planning (ACP); and, 3) the patient's preferred place of death and whether primary care involvement allows people to die in the place of preference. It is the second in a series that comprehensively examines the role of primary care practitioners at the end of life. This review will help inform the development of initiatives to improve EoLC in primary care and to improve the palliative care skills of health professionals providing such care.

## **METHODS**

We conducted a systematic review to critically appraise the effectiveness of care provided by GPs and GPNs in the care of patients approaching the end of life. A protocol for the search was generated by the team in consultation with a health librarian.

*Phenomena of interest:* We included studies of physical and psychosocial components of palliative care directly delivered through general practice by a GP and/or GPN; or multidisciplinary palliative care teams involving GPs or GPNs, or models of integrated care that directly involved a GP or GPN.



## **Inclusion criteria**

*Types of participants:* We sought studies of GPs and GPNs working within general practices. We included studies with patients aged  $\geq 18$  years, suffering from advanced malignant or non-malignant illness, no longer responding to curative or maintenance treatment, and who required treatment with a palliative intent.

*Types of studies:* This review included the following types of studies published in English:

1. Randomised individual or cluster controlled trials (RCTs)
2. Non-randomised controlled trials (CCTs)
3. Controlled before and after studies (CBAs)
4. Qualitative studies (phenomenology using semi-structured interviewing or focus groups) (QUALs)
5. Other (e.g. cohort studies, questionnaire studies)

We excluded papers that did not report research findings, including editorials and opinion pieces.

*Types of outcomes:* The overall review sought studies that included one or more of the following outcomes:

1. GP and/or GPN outcomes:
  - a. Extent of GP and/or GPN involvement in PC delivery
  - b. Type of care delivered by GP and/or GPN
  - c. Type of advanced conditions receiving PC from a GP or GPN
  - d. Promoters and barriers to delivery of PC by a GP or GPN
  - e. GP or GPN confidence in providing PC
  - f. GP or GPN gaps in knowledge in providing PC
2. Process outcomes:
  - a. Extent and nature of GP or GPN interactions with multidisciplinary teams including palliative care specialists and hospices in the delivery of palliative care

- b. Out of office hours care

3. Patient /carer Outcomes:

- a. Preferred place of death
- b. Satisfaction with care
- c. Symptom management including pain
- d. Quality of life
- e. Carer stress
- f. Advance care planning
- g. Psychosocial (mood, anxiety)

### **Search strategy**

We searched Medline, Psychinfo, Embase, Joanna Briggs Institute and Cochrane databases from 2000 to October 2017. The search strategy was based on that used in Mitchell's 2002 systematic review<sup>19</sup> and team discussion. The full search strategy is presented in Appendix 1.

The EndNote 8.0 reference package (Clarivate Analytics, USA) was used to manage references. The initial database search was by single review of Titles and Abstracts in these databases, and hand-searching references in systematic reviews was conducted by JFF, BW and HN. This initial search yielded 6209 articles after duplicates were removed. Titles and abstracts were then reviewed by both JFF and BW to 2014, and GM and HN to 2017: 5732 articles were excluded, leaving 474 articles for full text review. This included articles with a relevant title but no Abstract. Two authors conducted independent assessment of each article, following the protocol. Any disagreements were resolved by discussion between the two authors or by arbitration by a third author if necessary. A further 209 articles were excluded after this process, leaving 265 articles for analysis (figure 1). The Endnote library was downloaded into EPPI Reviewer4 (EPPI-Centre, University of London) a multi-user web-based application for managing and analyzing data for use in research synthesis.

### **Quality Assessment**

Each article was assessed by two authors for quality using a tool relevant to the study type: JADAD-RCT<sup>20</sup> for randomised controlled trials; the Critical Appraisal Skills Programme (CASP) for qualitative research;<sup>21</sup> the Newcastle-Ottawa Quality Assessment Scale (NOS) for cohort studies<sup>22</sup> and the NOS for cross-sectional studies.<sup>22</sup> Discrepancies in ratings were resolved by discussion, or by arbitration by a third author if necessary.

### **Analysis and reporting**

Because the number of articles was unexpectedly high we decided to subdivide the papers into categories that would inform a series of separate manuscripts. This approach was chosen to allow an appropriate level of depth for the analysis of the role of primary care at the end of life. All authors were asked to allocate the articles they reviewed to the different categories, and discussion between the authors ended in agreement for the five following categories:

1. GP and GPN performance of palliative care: symptom management;
2. GP and GPN performance of palliative care: patient and carer perspectives, Advance Care Planning, and the preferred place of death;
3. How do GPs and GPNs perceive their practice of palliative care, and do they do what they say they do?
4. Barriers and facilitators to involvement in palliative care: at the practitioner practice and system and policy level; and
5. Models of care aimed at encouraging participation in and integrating primary care practitioners into EoLC.

One paper was planned for each theme, with literature divided into these themes and then allocated to sub-categories. Authors worked in pairs to create a table of evidence and a brief written supporting statement for each sub-category. Papers that appeared relevant to multiple categories or sub-categories were included in multiple papers. The first author of each paper collated the sub-category reports into the final paper. As this is a systematic review, no ethical review was necessary. This paper addresses the second category: What are patient and carer perspectives on the role of GP and GPN; their impact on ACP, and on the preferred place of death?

## RESULTS

### Search results

From 6209 journal articles, 51 papers discussed: 1) patients' and carers' expectations of the role of primary care at EoL; 2) the contribution of GPs in ACP; and, 3) the preferred place of death of patients and whether primary care involvement allows people to die in the place of their preference (Figure 1).

*Insert figure 1 around here.*

### Consumer expectations of primary end of life care

Thirteen articles (eleven qualitative studies, two cross-sectional) discussed patient and carer expectations of primary care. Studies were conducted in the Netherlands,<sup>23-25</sup> Denmark,<sup>26 27</sup> Belgium,<sup>28</sup> the United Kingdom<sup>29-31</sup>, the United States<sup>32 33</sup>, and Australia<sup>34 35</sup>. The quality of studies was rated as moderate to high. Details of the aims, methods and quality of included studies are in Appendix 2.

Six key themes were identified: continuity of care; interpersonal relationships between the GP, patient and carer and between the GP and other health professionals; access and availability of primary care; GP clinical competence; multidisciplinary care; and holistic approach (Appendix 3.1).

**Continuity of care** was an important aspect of care<sup>23 27</sup> for patients and carers, and related to three issues: 1) *Relational continuity* of GP care with the preference for care to be provided by the same GP over time rather than different GPs;<sup>23 29 30 33</sup>. Next-of-kin valued an ongoing relationship with the GP, even after the death of the patient;<sup>28</sup> 2) *Informational continuity* to ensure the same patient information is available to all care providers to reduce the need for patients to continually retell their story;<sup>27 29</sup> and 3) *consistency of information provision* – all care providers should present patients with the same information.<sup>29</sup>

Patients and carers believed that **inter-professional communication** regarding diagnosis, treatment and prognosis facilitated good end-of-life care.<sup>23</sup> Whilst patients developed strong rapport and

relationships with health professionals in the acute care setting<sup>26</sup>, they needed to see overt collaboration between them, other agencies involved in EoLC provision and their GP to feel confident that all health professionals were working together.<sup>27</sup> The GP could be a key carer if the GP-patient relationship was established and effective. Some patients suggested that GPs should be proactive in engaging with health professionals such as oncologists and palliative care services, and that oncologists should inform patients of the important role of GPs in end-of-life care.<sup>26 27 31</sup>

Patients want a strong therapeutic relationship with their GP.<sup>24 33</sup> Consistently seeing the same GP contributed to a greater knowledge of the individual's needs and preferences, increasing trust and mutual understanding.<sup>28</sup> The GP would take time, be engaged and listen carefully, to deal with strong emotions, and to assist with ACP.<sup>32 33</sup> While patients observed a health professional-led approach to care, their preferred model was a partnership between health professionals, the patient and any relevant carers.<sup>29</sup> which would empower patients and their carers, and facilitate patient-centred care.

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The limited palliative care experience of some GPs was perceived by some patients and carers to impact on their ability to provide more than basic psychosocial and carer support.<sup>32</sup> Carers were reluctant to raise their own issues, thinking they did not want to bother the doctor. At the same time, the GP did not want to raise possible issues that the patient had not thought of.<sup>35</sup> Hence, important issues were never raised. Using a carer-completed checklist facilitated these complex consultations.<sup>34</sup>

**A GP's communication skills** were particularly valued by both patients and carers.<sup>27 29 30</sup> Attributes such as trustworthiness, respect, kindness, caring, sympathy, honesty and sensitivity fostered constructive and collaborative relationships between GPs, patients and carers.<sup>30</sup> Patients preferred GPs to be open and initiate discussions about end-of-life issues.<sup>24</sup> Clinicians, however, were challenged by the need to develop a common understanding among the patient, caregiver, and physician as to the meaning of the diagnosis, and to address their EoL concerns.<sup>32</sup>

**Access to and availability of GPs** and other health professionals was considered fundamental to good EoLC.<sup>23 27</sup> Patients needed to be able to see their GP when they needed to, and on time for clinic appointments.<sup>23 31</sup> As a patient deteriorated, it was essential that the GP was available out of hours and conducted home visits if the patient wished to remain at home.<sup>23 24 27 30</sup> Although lack of

time and availability were considered barriers to numerous aspects of care, communication, care planning and coordination, patients and carers appreciated GPs who made time to address their physical and psycho-social needs.<sup>23 31</sup>

***Patients expected GPs to be competent*** in diagnosing problems and managing their symptoms,<sup>23 32</sup> to be well informed about their condition, and to be aware of the side effects of treatment.<sup>23 24 26</sup> Patients wanted information about symptoms and their management to be shared with them.<sup>30</sup>

Patients' and carers' expected GPs would facilitate or enlist help from other agencies to enhance EoLC.<sup>30 31</sup> In particular, shared care between GPs, community services and specialist services (including palliative care services as needed) was desired.<sup>27 29 32</sup> One study highlighted the benefits of access to community support services to facilitate access to equipment and supplies.<sup>30</sup>

While some patients and carers identified the importance of the ***psychological, social and spiritual support*** which could be provided by GPs,<sup>30</sup> others had not considered that they might use the GP for non-biomedical or non-treatment-related issues.<sup>26</sup> They did not want to inconvenience or disturb a busy GP for what they considered 'minor matters', despite increasing psychosocial concerns as the disease progressed.<sup>26</sup> By contrast, some clinicians described managing patient care largely in terms of treating the disease.<sup>32</sup>

One study sought the characteristics considered most important at the end of life. Patients, carers and physicians consistently identified: preparation for end of life; feeling that one's life was complete; being treated as a whole person; management of symptoms and personal care.<sup>33</sup>

### **Advance care planning**

Nineteen articles were included in the review of EoLC focusing on the role of GPs in ACP. The included studies came mostly from high income countries: Australia,<sup>36-39</sup> Belgium,<sup>40-44</sup> Canada,<sup>45</sup> Netherlands,<sup>41 42 43</sup> Italy,<sup>42 43</sup> UK,<sup>46 47</sup>, and the US.<sup>48-52</sup> South Africa was the exception.<sup>53</sup> One study compared UK GPs with Netherlands specialist Nursing Home physicians.<sup>54</sup> All studies used a descriptive design. The quality was variable: qualitative studies rated between moderate to high;<sup>36 37 39</sup>

<sup>40 45 46 49 50</sup>, poor to high for cross-sectional studies;<sup>41 43 44 51 54</sup> and moderate to high for cohort studies.<sup>36 49 50</sup> (Appendix 2.2)

Two studies included patient perspectives or outcomes <sup>45 48</sup>. One study included a wide variety of health professionals including GPs, community nurses, palliative care specialists and nurses, psychogeriatricians and a wide range of allied health professionals, and volunteers.<sup>47</sup> Two studies included GPs' and community nurses' perspectives.<sup>46 53</sup> Four studies compared GPs and specialists.<sup>36 49 50 54</sup> Ten studies included GPs only.<sup>37 38 40-44 51 52</sup> Four key themes emerged from these studies: uncertainty about the timing of ACP; factors influencing GPs' completion of ACP; determinants of ACDs being implemented; and outcomes of EoLC if an ACP in place (Appendix 3.2) .

***Uncertainty about the timing of ACP.*** ACP is performed ad-hoc in the terminal phase, discussed but not documented, or not considered at all.<sup>41 43 44 51</sup> The unpredictability of the EoL trajectory and the absence of a clear beginning of the terminal phase for non-cancer patients created uncertainty among clinicians about initiating a discussion.<sup>40-42</sup> Consequently, for non-cancer patients, ACP often occurred in the last week of life <sup>41 51</sup> despite patients' preference to discuss EoL issues with their GP earlier.<sup>45</sup> Discharge from hospital was a commonly identified trigger for initiating ACP.<sup>41 46</sup> ACP is more likely to be completed if the patient was in hospital as opposed to the community, as the hospital treating doctors were more likely to recognise changing clinical status.<sup>46</sup> There was disagreement among GPs about introducing ACP at the time of diagnosis of dementia, compared with after that time.<sup>54</sup>

Several ***factors that influenced the GPs' completion of ACP*** were identified. An ACP was more likely to be completed if the GP was older and had more clinical experience;<sup>51</sup> if the GP was comfortable discussing ACP;<sup>42 51 52</sup> if they had appropriate education and training in ACP;<sup>36 37 40 45 46</sup> if the GP was involved and trained in palliative care;<sup>52</sup> and if they considered it their responsibility to raise the issue.<sup>54</sup> The quality of ACP was variable. Where EoL discussions took place, not all holistic aspects, such as spiritual and existential concerns, social issues and cultural differences, were discussed.<sup>42 51 52</sup> Lack of time was also described as a barrier to ACP.<sup>39</sup>

Patient characteristics and patient interest in ACP also influenced the GP's involvement. If patients lacked awareness of their diagnosis and prognosis or did not initiate such a discussion, ACP was often not raised by the GP.<sup>40</sup> GPs also found it difficult to introduce ACP to patients who are not already interested or informed about it.<sup>39</sup> Older patients with non-cancer diseases often had less detailed ACP discussions.<sup>42</sup> Despite these influences, patients want to discuss ACP with their GP but at a much earlier phase.<sup>45</sup>

Other factors that influenced completion or implementation of ACP were: concerns about the legal standing<sup>37 47</sup> and currency of ACP documents;<sup>53</sup> confusion about terminology and systems, particularly with substitute decision making,<sup>36</sup> uncertainty around validity of the multiple forms of ACP available,<sup>47</sup> concerns about making binding decisions about the future given the uncertainties of disease trajectories, and lack of awareness that ACP could be modified.<sup>37 46 47</sup>

Organisational and care setting factors influenced the completion of an ACP. Incorporating ACP as part of standard care, and having organisational protocols and systems for ACP, especially in residential care facilities, were important in increasing the use of ACPs.<sup>38 40</sup> ACPs were also more likely to be considered in the context of EoLC and in the provision of palliative care.<sup>42 46</sup>

There are multiple **determinants of whether the completed Advance Care Plans or Directive** are implemented. These included ACP factors such as availability, currency, and legality of the forms,<sup>37 47</sup> timing of ACP,<sup>41</sup> patient illness factors (quality of life of patient, level of functionality and prognostication); organisation and care setting factors (prioritising of life-sustaining treatments, policies and protocols to support use of ACP); awareness, and attitudes of health professionals and family to ACP (eg families' understanding of the disease progression, and GPs' desire to avoid family dissent).<sup>37</sup>

**Outcomes of End of Life care if an ACP is in place.** Where an ACP was in place and implemented, patient preferences and wishes were more likely to be followed.<sup>43</sup> Other patient outcomes of ACP included anticipated symptoms being identified earlier, greater control with symptom management,<sup>50</sup> greater patient satisfaction with the GP,<sup>48</sup> and increased support, contact and visits by GPs in the last



week.<sup>41 43</sup> Moreover, when an ACP was completed, patients were more likely to die in their preferred place of death.<sup>44</sup>

## **Place of Death**

Nineteen articles that evaluated if the GP's and GPN's role influenced dying in the preferred place of death were eligible for inclusion in the review. Four studies were multi-national,<sup>55-58</sup> The studies were based in Belgium,<sup>55-60</sup> the Netherlands,<sup>55 57 61 62</sup> Denmark,<sup>63-67</sup> Spain,<sup>56</sup> Italy,<sup>56</sup> the UK<sup>68-70</sup> and Canada.<sup>71-73</sup> (Appendix 2.3)

To explore relationships between GP and health professionals visits, patient demographics, and place of death, a range of study designs were employed including one case control (rated moderate quality),<sup>63 64</sup> cohort (rated moderate to good quality),<sup>55 61 62 71</sup> cross-sectional (quality variable),<sup>56 57 59 60 65-69 72 73</sup> and qualitative research (CASP scores 18<sup>70</sup> and 20<sup>58</sup>). (Appendix 2.3)

Many of the studies utilised cancer, GP or healthcare administrator registers.<sup>63-67 69 71 72</sup> Other studies obtained qualitative data from members of GP networks using a standardised questionnaire, patient records or practice registers.<sup>55-57 59-62</sup> There was one population-based cohort study. Another study obtained the perspectives of GPs and nurses (not GPNs) from different care settings<sup>58</sup> and another was a national postal survey to a random sample of GPs.<sup>68</sup> One study evaluated the effectiveness of a multi-disciplinary palliative and primary care team on outcomes including preferred place of death.<sup>73</sup> Two studies explored bereaved relatives' perspective on whether a patient died at their preferred place of death<sup>65 67</sup> with one of the studies further assessing the agreement between relatives, GPs, and community nurses on whether the preferred place of death changed during the disease trajectory.<sup>65</sup>

Most patients with advanced cancer preferred to die at home<sup>62 65</sup> whereas others opted for a nursing home, a hospice, a palliative care unit, or a hospital.<sup>62</sup> The oldest-old person (>85 years) more often preferred death in a nursing home compared with the younger-old.<sup>61</sup> In a recent study within GP networks of three European countries, a home death occurred in approximately half of all non-sudden

deaths.<sup>56</sup> The preference for a home death was found to weaken for some patients as the time to death approaches and their needs change.<sup>65</sup>

Four studies identified a significant association between home visits by GPs to patients with advanced cancer with the possibility of dying at home.<sup>63 64 66 72</sup> One study found that the odds of a hospital death decreased with the rate of home visits by a GP.<sup>63</sup> Similar findings on the likelihood of home death were found for home visits by community nurses to cancer patients.<sup>63 66</sup>

GPs were often unaware of a patients' preferred location to die.<sup>59</sup> GP knowledge of a patient's preferred place of death increased the likelihood that the patient would die there.<sup>59</sup> The GP was mainly informed of preferred place of death by patients themselves and/or by family members.<sup>62</sup> GPs were also more likely to be aware of a patient's preference if they were in the last months' of life and receiving care with a palliative care approach or specialist palliative care.<sup>62</sup>

High levels of continuity of care by a GP were associated with out-of-hospital deaths<sup>72</sup> and fewer emergency department visits.<sup>71</sup> Receiving palliative care from the GP was positively associated with dying at home and the preferred place of death.<sup>56</sup> In the UK, GPs who had higher clinical scores based on a palliative care approach, in conjunction with participation in ACP or preferred place of care documents, increased the likelihood that patients with advanced cancers would have a home death.<sup>68</sup>

The likelihood that a patient would die at their preferred location was increased by: being married and having children,<sup>63</sup> shorter length of previous hospital stays and fewer speciality visits.<sup>72</sup>

In Belgium, patients with dementia, especially those with severe dementia, more often died in a nursing home compared with older adults without dementia.<sup>60</sup> Patients with dementia were twice as likely to have a palliative treatment goal during the last week of life, and less likely to die in hospital compared to those without dementia. Further, patients with severe dementia were less likely to die in hospital compared with those suffering mild dementia, but are more likely to die in a care home. Patients with severe dementia were moderately less likely to die at home compared to those with mild dementia.<sup>60</sup> Only 12-15% of patients with dementia die at home.<sup>60</sup>

Circumstances do arise where GPs consider hospital admission is justified for people with a terminal condition, thereby increasing the likelihood of a hospital death. These include patient preference for a hospital admission, EoLC at the current care setting being inadequate, or acute medical situations requiring a hospital-based diagnosis or treatment is needed, such as an obstruction, sudden massive bleeding or uncontrolled pain.<sup>58</sup>

## **DISCUSSION**

In this component of a larger update of the systematic review by Mitchell<sup>19</sup> we explored the literature describing patient and carer expectations of primary care in EoLC and the role of GPs and GPNs in ACP and place of death.

Many GPs have a privileged relationship with their patients approaching EoL as a companions on their journeys.<sup>74</sup> With such privilege comes responsibility to provide the best care they can.

With limited specialist palliative care resources available in the community,<sup>75</sup> it is often GPs who provide and co-ordinate EoLC in collaboration with community-based support services.<sup>76</sup> This occurs in rural areas more frequently than in urban areas, often out of necessity.<sup>14</sup> There is a challenge to involve and support all GPs to provide as many aspects of optimal EoLC as is possible, including advance care planning, anticipatory care as illness burden increases, and care for patients in their preferred place as close to death as possible. Identification of people at risk of dying will help GPs to put care in place in a timely manner. Support services, however, must be available to help GPs and carers provide the requisite care that ensures death in the preferred place.

Of note is the complete absence of studies that examine the role of the GP practice nurse at the end of life. The studies identified focused exclusively on the GP role. This is to some extent explained by the GP's diagnostic role and responsibility for generating the treatment plan. While general practice

multidisciplinary care has been a feature for many years in the UK, and a role for GPNs in primary palliative care has been advocated in heart failure,<sup>77</sup> the concept has been embraced only relatively recently in some countries. In view of the low prevalence of dying patients in primary care, team-based activities and nursing priorities have been focused on providing advice and support to high prevalence conditions first, like diabetes.<sup>78</sup> Perhaps the roles that could be done by practice nurses are being performed by other primary care team members.

However, the increasing burden of multimorbidity provides a natural role for practice nurses in identifying people at risk of dying, introducing the idea of ACP as a routine part of health assessments, monitoring at risk people for the development of palliative care needs, and providing advice and support of people with those needs are natural nursing tasks. There is a paucity of literature in this regard, however in Australia work focusing on the role of practice nurses at the end of life is underway.<sup>79</sup> It is likely that literature around the role and the impact of practice nurses will flourish in the near future.

Given the dependence on their GP, people who are approaching end of life, and those caring for them, articulated expectations of their primary health professionals: competent and effective management of physical symptoms, communication that is open, honest and sensitive to the individual's preference for information,<sup>80</sup> and availability for them, particularly when deterioration occurs and urgent needs arise.

While most of the last year of life is spent being cared for in the community by primary health care providers,<sup>10 81</sup> complex disease and specific interventions increasingly necessitate shared care between GPs and specialists. This review demonstrates that patients want well-coordinated multidisciplinary care. They want their health professionals to work collaboratively, be well informed about what each is doing, and that the implications of treatment should be communicated to their GP.

In recent years, dying has often been medicalised and excised from 'normal life'. In recent years, there has been a shift back to viewing death as 'normal' and 'part of life'.<sup>82</sup> Assisted by policy shifts and recognition of the cost of EoLC in institutional settings, ACP has emerged since the 2002 systematic review.<sup>83</sup> ACP aims to provide planned, coordinated EoLC consistent with the preferences

of the patient, and which limits inappropriate interventions, has generated programs to articulate patients' wishes and identify appropriate surrogate decision makers.<sup>84</sup> Patients want to discuss their EoL wishes with their doctors, but demur, preferring their GP to raise these issues. However, some doctors prefer to wait for the patient to initiate such discussions – so nothing happens.<sup>85</sup>

Numerous patient and GP barriers to timely completion of advance care plans were identified in this review, largely related to uncertainty about when advance care planning should commence, especially in people with a non-malignant diagnosis where the dying trajectory is less clear and the potential need to discuss prognosis is not as pressing. The extent to which advance care plans were adhered to in EoLC was variable and related to the availability of the advance care directive, the illness causing the patient's death, and the setting of care. Concerns are expressed by specialist services about the quality of some advance care directives, and their limited use in many situations that are not specified in the document.<sup>86</sup> However, patients who have discussed their care with their GP and formally documented their wishes are more likely to receive such care than patients who have not.<sup>87</sup>

The preferred and actual place of death, and the role of GPs in supporting people to die in the community, has been the subject of increasing research in recent years. People are more likely to die in their usual place of residence (whether home or a residential aged care facility (ie care home) ) where higher levels of support, ready access to competent medical care and knowledge of the patient's preferences are present.<sup>59 63 64 66 72</sup> All of these functions are present in a competent GP. It is understood that circumstances and preferences for place of care and death can change, pre-emptive discussions and documentation of ACPs ensure that patients and carers are well prepared and supported for the terminal phase. However, any advance care planning is dependent upon the GP identifying patients who are at risk of dying and for whom a palliative approach to care is appropriate—a task not routinely adopted in general practice at this time.<sup>11 88</sup>

**Strengths and limitations:** Due to the heterogeneous nature of the research in this field, we conducted a narrative review. Much of the research is descriptive with few randomised controlled trials (RCTs) of interventions. This is due, in part, to many publications reporting service-wide

interventions where randomisation of institutions/services is difficult. RCTs are not always practical or ethically appropriate in end of life research and alternative well-designed controlled studies which effectively address potential biases, such as multiple baseline designs, are necessary.<sup>89</sup> This systematic review was also limited by our access to publications written in English only, as there was no capacity to translate non-English texts.

**Conclusion:** Access to palliative care is recognised as a right<sup>90</sup> and many countries have enacted laws to confirm this right.<sup>91</sup> Specialised resources in palliative care will always be limited, and GPs' role in providing palliative and EoLC should provide the foundation to achieve equity of access to palliative care. The challenge, however, is to ensure that GPs are confident and skilful to deliver all aspects of EoLC successfully. Patients and carers expect their primary care providers to adopt an holistic approach and to be competent in all aspects of palliative care. Such care will encompass ACP and facilitate dying in the place of preference. Systematically identifying people for whom a palliative approach is appropriate is likely to improve all aspects of care, including engagement in advance care planning and communicating about EoL. Further research to develop and validate tools to help identify people at risk of dying within the next 6-12 months would be beneficial.

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**Competing interest statement**

There are no competing interests to declare.

**Key words:** primary palliative care, general practice, patient experience, patient expectations, carer expectations, place of death, advance health directives, systematic review.

**Access to data**

The full protocol and dataset can be obtained on reasonable request from the corresponding author.

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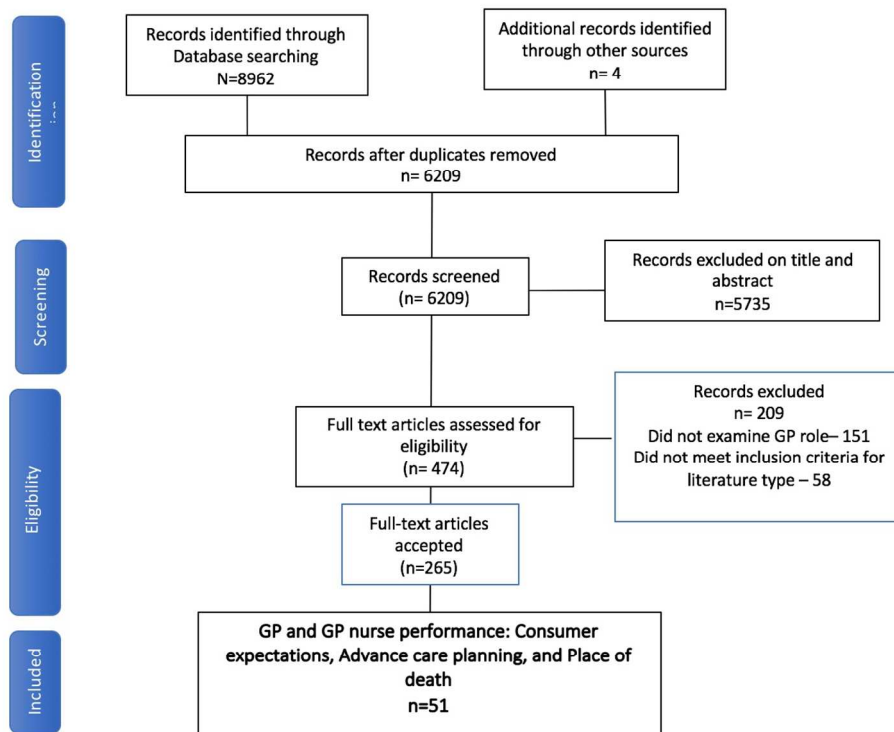


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram of included studies: general practitioner(GP) and general practice nurse (GPN) symptom management.

## **Appendix 1. Search strategy**

The search strategy for MEDLINE (Ovid) is as follows, with number of hits in brackets, and was adapted for other databases

- 1 exp Palliative Care/ (40025)
- 2 exp Terminal Care/ (41427)
- 3 exp Hospice Care/ (4594)
- 4 palliat\*.tw. (49152)
- 5 hospice\*.tw. (8644)
- 6 (terminal\* and (care or caring or ill\*)).tw. (14524)
- 7 ((advanced or 'end stage' or terminal\*) adj4 (disease\* or illness\* or cancer\* or malignan\*)).tw. (115084)
- 8 ('last year of life' or lyol or 'life's end' or 'end of life').tw. (12394)
- 9 or/1-8 (216562)
- 10 (child\* or adolescent\* or infant\* or baby or babies or neonat\* or juvenil\* or pediatric\* or paediatric\* or matern\*).ti. (1028881)
- 11 9 not 10 (208790)
- 12 exp Primary Health Care/ (78629)
- 13 exp General Practice/ (63643)
- 14 exp General Practitioners/ (1880)
- 15 exp Physicians, Family/ (14718)
- 16 exp Family Practice/ (60080)
- 17 general practice.tw. (28839)
- 18 (family practice or family medicine).tw. (13017)
- 19 (general practitioner\* or gp\* or general physician\*).tw. (146922)
- 20 (family physician\* or family doctor\* or family practitioner\*).tw. (16343)
- 21 or/12-20 (288767)
- 22 exp Family Nurse Practitioners/ (8)
- 23 exp Nurses, Community Health/ (46)
- 24 exp Patient Care Team/ (54259)
- 25 exp Nutritionists/ (49)

## *Symptom management by general practitioners*

- 26 exp Physical Therapists/ (329)
- 27 exp Social Work/ (15085)
- 28 exp Psychology/ (58272)
- 29 or/22-28 (125712)
- 30 11 and 21 (4215)
- 31 30 and 29 (366)
- 32 30 or 31 (4215)
- 33 limit 32 to English (3723)
- 34 limit 33 to yr="2000 -Current" (2666)

## Appendix 2: Details of the aims, methods and quality of included studies

Study, author, date & location	Study design & aim	Setting, sample size & participant characteristics	Methods	Quality assessment
<b>2.1 Consumer expectations of primary end of life care</b>				
Why are some patients in treatment for advanced cancer reluctant to consult their GP?  Aabom & Pfeiffer, 2009, <sup>26</sup> Denmark	Qualitative Aim: to analyse cancer patients' views and perspectives on the mechanisms and barriers to involving the GP in the late treatment phase of advanced cancer	Setting: Oncology outpatients, South Denmark Participants: 16/31 patients (51.6% response rate). 14 carers	Unstructured interviews on diagnosis process emphasising role of the GP Structured questions related to needs being met by healthcare system and unmet needs in daily life.	CASP <sup>1</sup> 19/20
Good end-of-life care according to patients and their GPs  Borgsteede at al., 2006, <sup>23</sup> Netherlands	Qualitative Aim: to explore the aspects valued by both patients and GPs in end-of-life (EOL) care at home, and to reflect upon results in the context of future developments in primary care	Setting: Dutch College of GPs Participants: 31 GPs. 30 patients	Interviews on disease history, experience with care at home, good care, ideal care.	CASP 20/20
Living with advanced heart failure: a prospective, community based study of patients and their carers  Boyd at al., 2004, <sup>29</sup> UK	Qualitative Aim: to describe how patients and carers view health and social care in the last year of life	Setting: Consultant identified heart failure patients, Scotland Participants: 20/35 patients (57.4% response rate). Their carers, GP, key professionals. Focus group n=16.	3 monthly semi-structured interviews up to 1 year. Care received and if needs met Focus Group: discussed key findings of interviews.	CASP 18/20
Helping lay carers of people with advanced cancer and their GPs to talk: An exploration of Australian users' views of a simple carer health checklist.  Burridge, Mitchell, Jiwa and Giris, 2011, <sup>34</sup> Australia.	Qualitative Aim: Describe the norms, assumptions and subtleties which govern caregiver-GP consultations, and explores factors affecting their interaction regarding caregivers' own health concerns.	Setting: Consultations between GPs and patients who are caring for a loved one with advanced cancer.  Participants – six caregivers, nineteen health professionals	End of study interviews relating to consultations about carer needs, facilitated by either a self-completed needs assessment checklist or normal care.	CASP 18/20

<p>Helping lay carers of cancer patients to talk.</p> <p>Burridge et al 2015,<sup>35</sup> Australia</p>	<p>Qualitative</p> <p>Aim: to describe the experience of using a patient completed checklist to facilitate communication between GPs and patients caring for people with advanced cancer.</p>	<p>Setting: Consultations between GPs and patients who are caring for a loved one with advanced cancer.</p> <p>Participants – six caregivers, nineteen health professionals</p>	<p>End of study interviews relating to consultations about carer needs, facilitated by either a self-completed needs assessment checklist or normal care.</p>	<p>CASP 18/20</p>
<p>Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources</p> <p>Carduff et al., 2014,<sup>31</sup> UK</p>	<p>Qualitative</p> <p>Aim: to explore barriers to, and strategies for identifying carers of people at the end of life in primary care and to understand why carers do not self-identify</p>	<p>Setting: Scotland</p> <p>Literature review 50 papers.</p> <p>Participants: 7 primary palliative care researchers. 3 carer focus groups n=15. 2 health professional focus groups n=8</p>	<p>Literature review of barriers to self-identifying as a carer and identifying carers providing EOL.</p> <p>Researcher workshop on carer's perception of their role, identity as a carer and multi-dimensional support needs.</p> <p>Carer focus groups to explore barriers to being identified as a carer, point at which carers see themselves as carers and available supports.</p> <p>Health professional focus groups to explore current practices in carer identification, support, links with local carer organisations.</p>	<p>CASP 18/20</p>
<p>Issues in end-of-life care: patient, caregiver, and clinician perceptions</p> <p>Farber et al., 2003,<sup>32</sup> USA</p>	<p>Qualitative</p> <p>Aim: to study perceptions of patients, caregivers and physicians who are already connected with one another in an EOL care experience.</p>	<p>Setting: community programs, Seattle</p> <p>Participants: 43 interviews with EOL patients and carers. 39 family practice clinicians.</p>	<p>Interviews on important issues related to living with illness, strategies / methods / approaches to deal with issues, effectiveness of these and doctor involvement with identified issues.</p>	<p>CASP 18/20</p>



<p>Valued aspects of primary palliative care: content analysis of bereaved carers' descriptions</p> <p>Grande et al., 2004,<sup>30</sup> UK</p>	<p>Qualitative</p> <p>Aim: to identify what informal carers valued in the palliative support provided by GPs and district nurses.</p>	<p>Setting: carers, Cambridge</p> <p>Participants: 60 bereaved carers</p>	<p>Carers asked to "tell the story" from first signs of illness until death.</p>	<p>CASP 18/20</p>
<p>The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin</p> <p>Michiels et al, 2007,<sup>28</sup> Belgium</p>	<p>Qualitative</p> <p>Aim: to explore terminal patients' perceptions of GPs' role in delivering continuous end-of-life care and identifying barriers to this.</p>	<p>Setting: Primary care, Belgium</p> <p>Participants: 17 terminally ill patients took part in first interview, 11 in a follow-up interview 3 months later</p>	<p>Face-to-face, semi-structured, in-depth interviews. Patients partners were invited to contribute when present.</p>	<p>CASP 15/20</p>
<p>Palliative care for cancer patients in a primary health care setting: bereaved relatives' experience, a qualitative group interview study</p> <p>Neergaard et al., 2008,<sup>27</sup> Denmark</p>	<p>Qualitative</p> <p>Aim: to analyse experiences and preferences of bereaved relatives to terminally ill cancer patients in a primary care setting to explore barriers and facilitators for delivery of good palliative home care.</p>	<p>Setting: Community nursing records, Aarhus County, Denmark</p> <p>Participants: 3 focus groups of relatives of recently deceased cancer patients n=14</p>	<p>Focus groups to explore role and management of the GP, discharge from hospital to home care, interpersonal relations of treating teams, organisation of palliative care and role of the relative.</p>	<p>CASP 17/20</p>
<p>Facilitators and barriers for GP-patient communication in palliative care</p> <p>Slort, Blankenstein et al., 2011,<sup>24</sup> Netherlands</p>	<p>Qualitative</p> <p>Aim: to obtain detailed information on facilitators and barriers for GP-patient communication in palliative care, to develop training programmes for GPs to improve their palliative care communication skills.</p>	<p>Setting: The Netherlands</p> <p>Participants: 2 GP focus groups. 6 semi-structured patient interviews. Questionnaire to EOL consultants n=55</p>	<p>GP focus groups to explore facilitators and barriers for GP-patient communication in palliative care. Interviews on perceptions of GP communication skills and attitudes. Questionnaires on barriers for GP-patient communication</p>	<p>CASP 17/20</p>

Factors considered important at the end of life by patients, family, physicians, and other care providers  Steinhauser et al., 2000, <sup>33</sup> USA	Cross sectional survey Aim: to determine factors considered important at the EOL by patients, families, physicians and other care providers	Setting: National Veterans Affairs (VA) database USA Participants: 340/444 VA patients (77% response rate). 332/465 bereaved VA relatives (71% response rate). Physicians 361/ 486 (74%) EOL health professionals 429/490 (88%)	Survey on important attributes of experience of EOL	NOS Cross-sectional: 2 9/10
Information needs of patients with incurable cancer  Voogt et al. <sup>28 28</sup> 2005, <sup>23</sup> Netherlands	Cross sectional survey/interviews Aim: to describe what patients with incurable cancer have been informed about disease-related topics and how they evaluate the quality of the information giving	Setting: South and Southwestern Netherlands Participants: 128/192 cancer patients (67% response rate).	Questionnaires: Problems and Needs in Palliative Care Questionnaire (PNPC); The Hospital and Anxiety Scale (HADS) ; and the adapted Utrecht Coping List.  Interviews about type and duration of the cancer, cancer therapy, other types of care received, contacts with health care professionals, patients appreciation of the information giving by the GP, clinical specialist, oncology nurses and non-specialist nurses.	NOS Cross-sectional: 7/10

## 2.2 Advance care planning

End-of-life care in a voluntary hospitalist model: effects on communication, processes of care, and patient symptoms.  Auerbach & Pantilat, 2004, <sup>50</sup> USA	Cohort study. Aim: To compare the end-of-life care provided by community physicians and hospitalists and assess the effects of hospitalists care on communication, care patterns, and outcomes of dying patients.	Setting: A community-based teaching hospital, San Francisco, USA. 5334 patients: 3715 (70%) cared for by community-based physicians and 1619 (30%) cared for by hospitalists. Of patients cared for by community-based physicians, 264 (7%) died; 77 patients (5%) of hospitalists died during the same period. Only 74 charts of hospitalist patients were available for abstraction; the same numbers of charts were randomly selected from patients of community physicians. Patient characteristics: Patients cared for by community physicians had a mean age of	Comparison of communication, care planning and symptom control documented in medical records.	NOS Cohort: <sup>4</sup> 4/9
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		<p>74.5 years and patients cared for by hospitalists had a mean age of 72.1 years. Ethnicity of patients cared for by community physicians: White 62% Black 14% Asian 8% Other 16%. Ethnicity of patients cared for by hospitalists: White 50% Black 18% Asian 11% Other 22%.</p> <p>Hospitalist/ Community Physician</p> <p>Characteristics: Five community based physicians were female with a mean age was 51 years. Three of the hospitalists were men and two were female and mean age 34 years.</p>		
<p>Advance care planning for cancer patients in primary care: A feasibility study.</p> <p>Boyd et al., 2010,<sup>46</sup> UK</p>	<p>Qualitative study.</p> <p>Aim: To assess the feasibility of implementing advance care planning in UK primary care.</p>	<p>Setting: General Practice.</p> <p>Convenience sampling.</p> <p>20 GPs and 8 district and practice nurses from 4 general practices in south-East Scotland. 1 practice = semi-rural, 2 practices = urban, 1 practice = suburban.</p>	<p>GPs and district and practice nurses attending one of four training sessions in four General practices on advance care planning were interviewed.</p>	CASP 15/20.
<p>The role of general practitioners. Australian Family Physician.</p> <p>Brown (2002),<sup>39</sup> Australia</p>	<p>Qualitative study.</p> <p>Aim: to explore the issues for GPs when introducing advance directives to their patients as a basis for further research into this process.</p>	<p>Setting: GPs and their patients in general practices in Adelaide, Australia.</p> <p>Five GPs and 26 patients from two practices participated. Of 26 patients, 19 were female, average age 77 years (57-93).</p>	<p>Analysis of interviews with 5 GPs before and after participating in the intervention. Demographic and clinical information about the patients who were introduced to Advance Care Planning.</p>	CASP 16/20
<p>Advance directives or living wills: Reflections of general practitioners and frail care coordinators in a small town in KwaZulu-Natal.</p> <p>Bull &amp; Mash, 2012,<sup>53</sup> South Africa</p>	<p>Qualitative study.</p> <p>To explore the knowledge and attitudes of GPs and frail care co-ordinators on the use of living wills in Howick, KwaZulu-Nata.</p>	<p>Setting: General Practice and Residential Aged Care. Convenience sampling of 7 of 8 GPs and 3 of 5 frail care coordinators (nurses) working in a small South African town comprising largely of white retirement population.</p>	<p>Analysis of interviews with GPs and nurses</p>	CASP 11/20

<p>Medical practitioners' knowledge and self-reported practices of substitute decision making and implementation of advance care plans.</p> <p>Cartwright, Montgomery, Rhee, Zwar &amp; Banbury,<sup>36</sup> Australia</p>	<p>Cross sectional study.</p> <p>Aim: To assess GP and specialist levels of knowledge, and related practice, with respect to ACP</p>	<p>Setting: General practice, private practice, community practice &amp; hospital setting</p> <p>Random selection of 650 GPs and 350 medical specialists from NSW, in specialties most likely to be involved in ACP, end-of-life decision making and acute resuscitation scenarios. This included acute care physicians (e.g. intensive care, emergency and anaesthetics), geriatricians, palliative care physicians and oncologists. Response rate from specialists 34% (n = 110), GP 24% (n = 150) and overall rate of 27% (n = 260). 52% of GPs and 78% of specialists were male. 16% of participants were &lt;40 years age, 18% were 60 years or older. 62% reported &gt;20 years as medical practitioner, compared to 13% less than 10 years.</p>	<p>Responses to questionnaire</p>	<p>NOS Cross-sectional: 3/10</p>
<p>Barriers to advance care planning in cancer, heart failure and dementia patients: A focus group study on general practitioners' views and experiences.</p> <p>De Vleminck et al., 2014,<sup>40</sup> Belgium</p>	<p>Qualitative study.</p> <p>Aim: To identify the barriers, from GPs' perspective, to initiating advanced care plans and to gain insight into any differences in barriers between the trajectories of patients with cancer, heart failure and dementia.</p>	<p>Setting: General practice.</p> <p>Purposive sampling. 5 focus groups with 36 GPs. Median age of GPs was 49 years (range 29-69). Males 75% and females 25%. 9 urban, 27 rural.</p>	<p>Analysis of focus group with GPs.</p>	<p>CASP 18/20</p>
<p>End-of-Life Decisions: A Cross-National Study of Treatment Preference Discussions and Surrogate Decision-Maker Appointments.</p> <p>Evans et al., 2013,<sup>43</sup> Italy, Spain, Belgium, Netherlands</p>	<p>Cross sectional study.</p> <p>Aim: To estimate and compare the prevalence of GP-patient medical EoL treatment preference discussions and patients' appointment of surrogate decision- makers in four European countries; and to examine country specific factors associated with treatment preference discussions and surrogate appointments.</p>	<p>Setting: Primary care in four European countries.</p> <p>GPs in sentinel networks. 4,396 deaths (Italy n = 1,808, Spain n = 379, Belgium n = 1,556, the Netherlands n = 653). The mean age of death was 80, 81, 79 and 77 for Italian, Spanish, Belgian and Dutch patients respectively.</p>	<p>Self-report questionnaire.</p>	<p>NOS Cross-sectional: 2/10</p>

<p><b>End-of-life communication: A retrospective survey of representative general practitioner networks in four countries.</b></p> <p>Evans, N., et al., 2014,<sup>42</sup> Italy, Spain, Belgium, Netherlands</p>	<p>Cross sectional study. <b>Aim:</b> To estimate and compare the prevalence of GP-patient discussion of different end-of-life topics before patients' deaths in four European countries, and to analyze associations between discussions and patient and care characteristics for each country.</p>	<p>Setting: Primary care in four European countries. GPs in sentinel networks. 4396 deaths (Italy n = 1808, Spain n = 379, Belgium n = 1556, and The Netherlands n = 653). Most deaths occurred in older than 85 years (32–44%). Most common cause of death was cancer (37–52%).</p>	<p>Self-report questionnaire.</p>	<p>NOS Cross-sectional: 3/10</p>
<p>Frequency and perceived competence in providing palliative care to terminally ill patients: A survey of primary care physicians.</p> <p>Farber, Urban, Collier, Metzger, Weiner &amp; Boyer, 2004,<sup>52</sup> USA</p>	<p>Cross sectional study. <b>Aim:</b> To ascertain how frequently Primary Care Physicians are involved in each of the different components in end-of-life care and their perceived competence in each of these areas.</p>	<p>Setting: General Practice. 1000 randomly selected practicing family practitioners and internists in the USA, identified through the American Medical Association master file. Response rate 485 (462/972). Mean age 46 years and 74% male, 24% female.</p>	<p>Self-report questionnaire.</p>	<p>NOS Cross-sectional: 4/10</p>
<p>Advance care planning in Belgium and the Netherlands: A nationwide retrospective study via sentinel networks of general practitioners.</p> <p>Meeussen et al., 2011,<sup>41</sup> Belgium &amp; Netherlands.</p>	<p>Cross sectional study. <b>Aim:</b> To examine the prevalence and characteristics of ACP in two countries and identify associated factors with completion or non-completion of ACP.</p>	<p>Setting: General practice, home, hospice and hospital. Consecutive patients registered on a national mortality database by GPs over a one year period. GPs practices in Belgium included 156 practices and 45 practices in Netherlands. Patient characteristics: Age at death &lt;65yrs 16.8%; 65- 79yrs 29.9%; 80 yrs and greater comprised of 53.3%.The cause of death was 42% with a malignancy; 17.7% with cardiovascular disease; 8% with respiratory disease, 4.7% with a nervous system issue, 6.9% with stroke and 20.4% other. Male patients comprised of 46.5%, females 53.5%.</p>	<p>Validated measurement tool used to measured existence and content of advance care plans in place and identify which patients and health care characteristics were associated with ACP occurring.</p>	<p>NOS Cross-sectional: 8/10</p>
<p>Enhancing palliative care in rural Australia: The residential aged care setting.</p> <p>Mitchell, Nicholson,</p>	<p>Cross sectional study. <b>Aim:</b> To assess the needs of, and quality of palliative care delivered to residents of 16 residential aged care facilities in</p>	<p>Setting: Residential Aged Care facilities in rural southern Australia. Records audit of 723 residents (31% male, 67% female, 2% unknown; 78% were 80 years or older), and focus groups with 28</p>	<p>Data collection (audit vs palliative care standards) and focus groups</p>	<p>NOS Cross-sectional: 7/10</p>

McDonald & Bucetti, 2011, <sup>38</sup> Australia	rural southern Australia; and (ii) identify the needs of care staff to facilitate the delivery of quality palliative care.	relatives (82% female) of residents and 27 health care professionals (7 registered nurses, 15 other nurses, 2 ancillary staff, 1 counsellor, 2 palliative care nurses, 2 GPs)		
Why are advance care planning decisions not implemented? Insights from interviews with Australian general practitioners.  Rhee, Zwar & Kemp, 2013, <sup>37</sup> Australia	Qualitative study. Aim: To explore their experience of Australian GPs in implementing ACPs and perspectives on the factors that influences the success of their implementation.	Setting: General practice Purposive sampling of 17 GPs (11 male, 6 female). 3 GPs were <40 years of age, 11 were 40-60 years age, 3 were >60 years age.	Analysis of interviews with GPs.	CASP 16/20.
Awareness of do-not-resuscitate orders: what do patients know and want?  Robinson et al., 2012, <sup>45</sup> Canada	Cross sectional study. Aim: To determine outpatients' awareness of the terms do not resuscitate or DNR and to determine their preferences regarding when, where, and with whom they wished to have DNR discussions.	Setting: General practice - four primary care physician offices. Consecutive sampling of patients, a response rate of 90% (386 / 429). Patient characteristics: age 40-49 years = 36%, 50-59 years = 27%, 60-69 years = 18%, 70-79 years = 13%, 80-89 years = 5% and 90+ = 1%. Ethnicity of participants included; Aboriginal 2%, White 76%, East Asian 13%, South east Asian 2%, South Asian 3% and Other 4%. The majority of participants were female (62%), male (38%).	Self-report questionnaire tool.	NOS Cross-sectional: 5/10
A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but'.  Robinson et al., 2013, <sup>47</sup> Canada	Qualitative study. Aim: To examine critically the views and experiences of a wide range of professionals, clinical and non-clinical, on ACP in two clinical areas, dementia and palliative care, where professionals may be more likely to introduce it due to a future loss of mental capacity and the presence of a terminal illness.	Setting: Other - palliative and dementia care. Respondents drawn from palliative care, primary care, dementia care services, social services, the voluntary sector and legal professionals. Purposive sampling with focus groups and interviews.	Analysis of focus groups and interviews.	CASP 18/20

<p>The effect of discussions about advance directives on patients' satisfaction with primary care.</p> <p>Roter, Larson, Fischer, Arnold &amp; Tulsky, 2000,<sup>49</sup> USA</p>	<p>Qualitative descriptive study.</p> <p>Aim: To explore best practices by describing what physicians who are considered expert in the area of end of-life bioethics or medical communication do when discussing ADs with their patients and to explore the ways in which best practices of the expert group might differ in content or style from normative practice derived from primary care physicians' discussions of ADs with their patients collected as part of an earlier study.</p>	<p>Setting: Primary Care.</p> <p>Convenience sampling. 18/20 expert physicians enrolled 48 patients and 56/60 non expert physicians enrolled 56/81 patients.</p> <p>Patient characteristics: Patients in expert group median age was 74 yrs (range 62-90) compared to 72 yrs (range 58 - 88) in non-expert group. Ethnicity of patients in expert group included 78% white and non-expert group included 84%. 54% were male in expert group and 68% male in non-expert group.</p> <p>GP Characteristics: Age of expert group ranged from 37-74 yrs (medium 49) and for the non-expert group the range was 58-88 (medium 72yrs). Ethnicity of the expert group was 100% white and non-expert group included 93% white. 72% of expert group and 56% of non-expert group were male.</p>	<p>Discussion on Advance Care Directives by expert physicians' vs non expert physicians.</p>	<p>CASP 18/20</p>
<p>Physician Knowledge, Attitude, and Experience With Advance Care Planning, Palliative Care, and Hospice: Results of a Primary Care Survey.</p> <p>Snyder, Hazelett, Allen &amp; Radwany, 2013,<sup>51</sup> USA</p>	<p>Cross sectional study</p> <p>Aim: To evaluate primary care physicians' understanding of and experience with advance care planning (ACP), palliative care, and hospice and how this might affect their utilization of these services.</p>	<p>Setting: General practice.</p> <p>Convenience sample from database of physicians associated with a local medical school. 158/372 returned questionnaire, 35 excluded as they were subspecialists.</p> <p>GP characteristics: Mean age of 50 yrs. Ethnicity included; African American 1.7% Hispanic 1% Asian American 3.4% Caucasian / White 91.4% and Other 1%. 64% were male and 36% female.</p>	<p>Self-report questionnaire.</p>	<p>NOS Cross-sectional: 4/10</p>

<p>The effect of discussions about advance directives on patients' satisfaction with primary care.</p> <p>Tierney et al., 2001,<sup>48</sup> USA</p>	<p>Cohort study.</p> <p>Aim: To assess the impact of discussions of advance directives on patients' satisfaction with their primary care physicians and outpatient visits.</p>	<p>Setting: General practice - hospital-based academic primary care general internal medicine practice that mainly serves inner-city indigent patients. Consecutive sampling. 668 patients included but number of the eligibility was not included nor refusals. They were cared for by 87 physicians.</p> <p>Patient characteristics: mean age = 65, female = 67%, African American = 65%.</p> <p>Physician characteristics: 67% male; 81% US medical school graduates; 33% faculty member.</p>	<p>Measurement of satisfaction with primary care physician and satisfaction with the primary care consultation immediately after.</p>	<p>NOS Cohort: 8/9</p>
<p>Initiating advance care planning on end of life issues in dementia: Ambiguity among UK and Dutch physicians.</p> <p>Van der Steen, Galway, Carter and Brazil, 2016,<sup>54</sup> Netherlands and UK</p>	<p>Cohort study</p> <p>Identify differences between Netherlands and UK physicians who provide end of life care to dementia patients agree on need for early introduction of ACP after diagnosis of dementia.</p>	<p>Setting: Elderly care physicians in Netherlands (N) (n=188), GPs in Northern Ireland (NI) (n=133).</p> <p>Participant characteristics: female 67%N; 42.6 NI; Similar age and years in practice; More part time N than NI. N Higher exposure to dying dementia patients N than NI (P&lt;0.001), and time spent practicing in nursing homes (p&lt;0.001)</p>	<p>Questionnaire survey</p>	<p>NOS Cross-Sectional</p> <p>5/10</p>
<p>Advance directives and physicians' orders in nursing home residents with dementia in Flanders, Belgium: Prevalence and associated outcomes.</p> <p>Vandervoort et al.,2012,<sup>44</sup> Belgium</p>	<p>Cross sectional study.</p> <p>Aim: To describe the prevalence of documented ACP among RACS with dementia in Flanders, Belgium, and associated clinical characteristics and outcomes.</p>	<p>Setting: Residential Aged Care. Consecutive sampling. Participating homes identified all residents who had died over the last two months. All nursing homes in Flanders, Belgium were asked to participate - response rate 58% (345/594). 764 residents were identified. 59.8% were 85 years or older at time of death, 72.4% were female.</p>	<p>Structured questionnaire sent to nurses closely involved in the deceased resident's care.</p>	<p>NOS Cross-sectional: 6/10</p>



## 2.3 Place of Death

Does persistent involvement by the GP improve palliative care at home for end-stage cancer patients?  Aabom et al. 2006, <sup>64</sup> Denmark	Case control Aim: To analyse the effect of GP home visits on the granting of a terminal declaration (TD) and on place of death.	Setting: Register linkage from five Danish healthcare registers in the period 1997-1998 Participants: 2025 patients with cancer as the primary cause of death	Retrospective case record review on number of services provided by GPs, registration of terminal declarations, GPs home visits, hospitalisations, date of death, causes of death, age at death.	NOS Case Control: <sup>3</sup> 6/9
Population-based study of place of death of patients with cancer: implications for GPs.  Aabom et al. 2005, <sup>63</sup> Denmark	Case control Aim: To explore factors associated with place of death in an unselected population of patients dying from cancer and, in particular, to explore whether GP and community nurse services were associated with place of death adjusted for patient-related factors.	Setting: Register linkage from six Danish healthcare registers between 1 January 1996 and 31 December 1998. Participants: Patients residing at home (n = 4092) three months prior to death and who died due to cancer.	Retrospective case record review on place of death, cancer diagnosis, age at diagnosis, number of GP consultations and home visits, community nurse home visits, hospitalisations, patient demographics.	NOS Case Control: 6/9
Use of palliative care services and general practitioner visits at the end of life in The Netherlands and Belgium.  Abarshi et al. 2011, <sup>55</sup> The Netherlands and Belgium	Cohort Aim: To compare the frequency of GP visits and use of palliative care services at the end of life in two European countries and identify the associated factors	Setting: the Dutch and Belgian Sentinel GP Networks consisted of 45 (including 67 GPs) and 181 (including 205 GPs) regular general practices. Participants: 543 registered patients who died at home or in a care home within a one-year period	Questionnaire completed by the GP on patient demographics, cause of death, preferred and actual place of death, longest place of residence, care characteristics in last 3 months of life, GPs awareness of place of death, treatment goal in last week of life.	NOS Cohort: 7/9

<p>The oldest old and GP end-of-life care in the Dutch community: a nationwide study.</p> <p>Abarshi et al. 2010,<sup>61</sup> The Netherlands</p>	<p>Cohort</p> <p>Aim: This study explores differences in end-of-life care of the oldest (<math>\geq 85</math> years) versus the younger (65–84 years) old; testing the hypothesis that age could be an independent correlate of receiving specialised palliative care services (SPCS), having palliative-centred treatment and dying in a preferred place</p>	<p>Setting: the Dutch Sentinel GP Networks consisted of 67 GPs from 1 January 2005 to 31 December 2008</p> <p>Participants: Registered patients <math>\geq 65</math> years (<math>n = 990</math>), who died non-suddenly.</p>	<p>Questionnaire where the GP was asked to provide information about the care the patient received in the last 3 months of life including demographics; cause of death, main treatment goal in the last week of life, receipt of specialist palliative care, GPs awareness of preferred place of death, patient's actual place of death.</p>	<p>NOS Cohort: 6/9</p>
<p>General practitioner awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands.</p> <p>Abarshi et al. 2009,<sup>62</sup> The Netherlands</p>	<p>Cohort</p> <p>Aim: This study sought to examine GP awareness of the preferred place of their patients' death, and whether this awareness was related to patient and care characteristics. Furthermore, it assessed the extent to which those patients whose GPs knew their preferred places of death actually died there.</p>	<p>Setting: the Dutch Sentinel GP Networks consisted of 45 (including 67-70 GPs) general practices</p> <p>Participants: Registered patients <math>\geq 1</math> years (<math>n = 637</math>), who died non-suddenly.</p>	<p>Questionnaire where the GP was asked to provide information on patient demographic, care received within the last three months of life, cause of death, preferred place of death (POD); GP awareness of POD, involvement of specialist palliative care services, goal of the patient's treatment, the main focus of care, the place of care, and the actual POD</p>	<p>NOS Cohort: 6/9</p>
<p>Are family physician visits and continuity of care associated with acute care use at end-of-life? A population-based cohort study of homecare cancer patients.</p> <p>Almaawiy et al. 2014,<sup>71</sup> Canada</p>	<p>Cohort</p> <p>Aim: Among end-of-life homecare cancer patients, to investigate the association of family physician continuity with location of death, hospitalisation and emergency department visits in the last 2 weeks of life while controlling for nursing hours.</p>	<p>Setting: Data linkage from seven administrative health databases in Ontario, Canada:</p> <p>Participants: Registered patients (<math>n = 9467</math>) who died in 2006, with a confirmed cancer diagnosis, <math>\geq 18</math> years, and have a valid provincial health insurance number.</p>	<p>Retrospective case record review on date and cause of death, specialist and GP visits, hospital and emergency department admissions, comorbidities, place of death, income and rurality, homecare provision.</p>	<p>NOS Cohort: 8/9</p>

<p>Primary care continuity and location of death for those with cancer.</p> <p>Burge et al. 2003,<sup>72</sup> Canada</p>	<p>Cross-sectional Aim: To examine the association between family physician continuity of care and the location of death for patients with cancer</p>	<p>Setting: Four linked administrative health databases spanning 6 years of information (1992-1997) Participants: Patients (n = 9714) who died of cancer from 1992 to 1997 and had made at least three ambulatory visits to a family physician.</p>	<p>Retrospective case record review on patient demographics, ambulatory visits to GP, place of death.</p>	<p>NOS Cross-sectional: 8/10</p>
<p>Actual and preferred place of death of home-dwelling patients in four European countries: making sense of quality indicators.</p> <p>De Roo et al. 2014,<sup>56</sup> Belgium, The Netherlands, Spain, Italy</p>	<p>Cross-sectional Aim: To describe whether “the percentage of patients dying at home” and “the percentage of patients who died in their place of preference” are feasible and informative quality indicators.,</p>	<p>Setting: European Sentinel GP Networks Monitoring End-of-Life Care (EURO SENTI-MELC) study in four European countries, namely Belgium, the Netherlands, Spain and Italy collected in 2009 (all countries except Spain), 2010 (all four countries) and 2011 (Spain only). Participants: Patients (n = 3752, aged ≥ 18 years), who were part of a GP's practice and had died non-suddenly according to their GP.</p>	<p>Retrospective case record review, a GP questionnaire on patients preferred place of death, provision of palliative care by the GP, care goals two to four weeks prior to death</p>	<p>NOS Cross-sectional: 4/10</p>
<p>What progress has been made towards implementing national guidance on end of life care? A national survey of UK general practices.</p> <p>Hughes et al. 2010,<sup>68</sup> United Kingdom</p>	<p>Cross-sectional Aim: To establish the extent to which UK primary care has adopted recommended practices on supportive and palliative care of adults with cancer, and to relate this to participation in national initiatives.</p>	<p>Setting: A random sample of UK general practices (England, Wales, Scotland and Northern Ireland) Participants: 2096 GP practices, 60.0% response rate</p>	<p>Questionnaire to GPs derived from principles in the NICE guidance and the Scottish Partnership for Palliative Care and on practice organization, clinical practice, and quality.</p>	<p>NOS Cross-sectional: 5/10</p>
<p>Enhancing family physician capacity to deliver quality palliative home care: an end-of-life, shared-care model.</p> <p>Marshall et al. 2008,<sup>73</sup> Canada</p>	<p>Cross-sectional Aim: Improve access to palliative care through use of screening criteria and case finding, improve general practitioners knowledge , skills and confidence in palliative care through practice-based education, improve the quality of home palliative care</p>	<p>Setting: Three GP practices in Ontario Participants: 22 family physicians and 36 nurses or other practice staff</p>	<p>Annual referral rates by GP to a Enhanced Palliative Care Team (EPCT), recipients of contact by the EPCT, attendance by practice staff at educational sessions, patients preference for place of death, length of patient participation in the EPCT program.</p>	<p>NOS Cross-sectional: 7/10</p>

<p>Care of people dying with malignant and cardiorespiratory disease in general practice.</p> <p>McKinley et al. 2004,<sup>69</sup> United Kingdom</p>	<p>Cross-sectional</p> <p>Aim: Compare general practice care in the last year of life with malignant and cardiorespiratory disease.</p>	<p>Setting: Two Leicestershire general practices: one inner-city, one semi-rural; total practice population of 26,000 people</p> <p>Participants: patients registered with participating general practices who died with malignant or cardiorespiratory disease between 1 August 2000 and 31 July 2002</p>	<p>Retrospective case record review on patient demographics, medical history, cause of death, any palliative care provision, medications.</p>	<p>NOS Cross-sectional: 7/10</p>
<p>Older people dying with dementia: a nationwide study.</p> <p>Meeussen et al. 2012,<sup>60</sup> Belgium</p>	<p>Cross-sectional</p> <p>Aim: Describe how older people die with mild or severe dementia, and to compare with patients dying without dementia</p>	<p>Setting: sentinel network of general practitioners (n= 172 GP practices) in Belgium</p> <p>Participants: Registered patients (aged &gt; 1 years) with GP diagnosed dementia (n=338) and patients without dementia (n=770) who died in 2008.</p>	<p>Retrospective case record review on medical care processes (GP and palliative care service provision, hospitalisation, treatment goals), communication processes (GP-patient conversations on medical treatment, decision making, and place of death), dying process (patients decision making capability in last week of life, and functional status, place of death)</p>	<p>NOS Cross-sectional: 8/10</p>
<p>End-of-life care and circumstances of death in patients dying as a result of cancer in Belgium and the Netherlands: a retrospective comparative study.</p> <p>Meeussen et al. 2011,<sup>57</sup> Belgium and the Netherlands</p>	<p>Cross-sectional</p> <p>Aim: Describe GP end of life care and circumstances of death of patients dying with cancer in Belgium and the Netherlands.</p>	<p>Setting: sentinel networks of general practitioners in Belgium (n= 172 GP practices) and the Netherlands. (n= 45 GP practices)</p> <p>Participants: Registered patients (aged &gt; 1 years) with diagnosed cancer (n=442) who had a non-sudden death in 2008.</p>	<p>Retrospective case record review and GP questionnaire on medical care processes (GP and palliative care service provision, hospitalisation, treatment goals), communication processes (GP-patient conversations on medical treatment, decision making, and place of death), dying process (patients decision making capability in last week of life, and physical and psychological stress in last week of life, symptoms in last week of life, place of death)</p>	<p>NOS Cross-sectional: 8/10</p>
<p>GPs' awareness of patients' preference for place of death.</p> <p>Meeussen et al. 2009,<sup>59</sup></p>	<p>Cross-sectional</p> <p>Aim: To examine how often GPs are informed about patients' preferred place of death, by</p>	<p>Setting: sentinel networks of general practitioners in Belgium (n= 174 GP practices)</p> <p>Participants: Registered patients (aged &gt;</p>	<p>Retrospective case record review and GP questionnaire on age at death, patient demographics, cause of death, and place of</p>	<p>NOS Cross-sectional: 8/10</p>

Belgium	whom and for which patients, and to study the expressed preferred place of death and how often patients die at their preferred place.	1 years) (n=798) who had a non-sudden death in 2006.	death, GPs knowledge of patient's preferred place of death, main treatment goal, palliative care received, involvement of informal caregivers, physical, psychosocial, and spiritual (existential/religious) care provision, number of contacts between GP and patient, hospitalisations.	
Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England.  Munday et al. 2009, <sup>70</sup> United Kingdom	Qualitative Aim: How primary care professionals undertake sensitive discussions about patient preferences at the end of life. Describe general practitioners' and community nurses' perceptions and experiences of exploring patients' preferred place of death.	Setting: 15 general practices participating in the Gold Standards Framework for palliative care from three areas in central England Participants: 17 general practitioners and 19 community nurses (16 district nurses, three clinical nurse specialists).	Semi-structured interviews with GPs and community nurses on broad topics related to preferred place of death	CASP Qualitative: 18/20
Preference for place-of-death among terminally ill cancer patients in Denmark.  Neergaard et al. 2011, <sup>65</sup> Denmark	Cross-sectional Aim: To describe where terminally ill Danish cancer patients prefer to die and to determine if their preference changed during the palliative period.	Setting: General Practices in Aarhus County, Denmark Participants: Adults (n=599) who died from cancer from 1 March to 30 November 2006 and who had received palliative home care. Additional participants were bereaved relatives, GPs and Community Nurses	Retrospective case record review on patient demographics, cancer diagnosis, place of death. Questionnaire provided to GP, community nurse and bereaved relative on patients preferred place of death during the trajectory of their illness.	NOS Cross-sectional: 6/10
Associations between successful palliative trajectories, place of death and GP involvement.  Neergaard et al. 2010, <sup>67</sup> Denmark	Cross-sectional Aim: To examine associations between bereaved relatives' evaluation of palliative cancer trajectories, place of death, and GP involvement.	Setting: General Practices in Aarhus County, Denmark Participants: Adults (n=153) who died from cancer from January to July 2007. Additional participants were bereaved relatives and patients GPs	Retrospective case record review on patient demographics, cancer diagnosis, place of death, number of GP home visits. Questionnaire provided to GP on involvement, unplanned home visits, extent GP knew patient, plan for out-of-office contact, GP contact with relatives,	NOS Cross-sectional: 5/10

			home care nurse and specialist team involvement. Questionnaire provided to bereaved relative on their relatives demographics, relation to deceased, if lived with patient, and their evaluation of the patient's palliative trajectory.	
Associations between home death and GP involvement in palliative cancer care.  Neergaard et al. 2009, <sup>66</sup> Denmark	Cross-sectional Aim: To describe cancer patients in palliative home care in relation to demographic characteristics, the palliative pathway, and degree of GP involvement.	Setting: General Practices in Aarhus County, Denmark Participants: Adults (n=333, response rate 63.2%) who died from cancer from 1 March to 30 November 2006 and who had received palliative home care. Additional participants were bereaved relatives, and patients GPs	Retrospective case record review on patient demographics, cancer diagnosis, place of death, number of GP home visits. Questionnaire provided to GP on patient demographics, involvement, unplanned home visits, extent GP knew patient, plan for out-of-office contact, GP contact with relatives, home care nurse and specialist team involvement.	NOS Cross-sectional: 8/10
What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses.  Reyniers et al. 2014, <sup>58</sup> Belgium	Qualitative Aim: To explore the perspectives of nurses from nursing homes, home care and hospitals, and family physicians concerning hospital admissions at the end of life and the circumstances in which they consider them to be justified	Setting: conference rooms in a hotel or locations where participants usually met, between February and June 2012, Belgium Participants: family physicians (n = 39), nurses (n = 23) from different care settings (nursing home, home care and hospital)	Focus groups about what justifies the admission of a terminally ill patient to hospital, prompted by vignettes describing three different cases, and on the key factors in deciding whether or not a hospital admission was justified.	CASP Qualitative: 20/20
<sup>1</sup> CASP: Critical Appraisal Skills Programme qualitative checklist <a href="http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf">http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf</a> <sup>2</sup> <b>NOS: Newcastle-Ottawa Scale Cross-sectional: This scale was adapted from the Newcastle-Ottawa Quality Assessment Scale for cohort studies by Herzog R et al , BMC Public Health201313:154. DOI: 10.1186/1471-2458-13-154</b> <sup>3</sup> NOS: Newcastle-Ottawa Scale Case-control: <a href="http://www.ohri.ca/programs/clinical_epidemiology/nos_manual.pdf">http://www.ohri.ca/programs/clinical_epidemiology/nos_manual.pdf</a> <sup>4</sup> NOS: Newcastle-Ottawa Scale Cohort: <a href="http://www.ohri.ca/programs/clinical_epidemiology/nos_manual.pdf">http://www.ohri.ca/programs/clinical_epidemiology/nos_manual.pdf</a>				

## Appendix 3 Evidence supporting the impact of general practitioners and general practice nurses of patient and carer expectations, advance care planning and place of death

Table 3.1 A description of the themes related to patient and carer expectations of general practitioners at end of life in primary care literature	
1. Continuity of care	<ul style="list-style-type: none"> <li>Continuity of care<sup>23 28</sup></li> <li>Cooperation and working together, referrals<sup>23 26</sup></li> <li>Relational continuity: having an ongoing relationship with the same GP<sup>23 29 30 33</sup></li> <li>Informational continuity: use of information on past events and personal circumstances to provide care<sup>27-29</sup></li> <li>Importance of shared care model<sup>29</sup></li> </ul>
2. a. Interpersonal relationships between the GP, patient and carer	<ul style="list-style-type: none"> <li>Cooperation and working together<sup>23 27</sup></li> <li>Communication style is important, sensitivity, empathic style<sup>27 29 30</sup></li> <li>Collaborative approach<sup>30</sup></li> <li>GP/carers relationship important<sup>33</sup></li> <li>Sensitive communication about EOL<sup>32</sup></li> <li>Collaborative approach (patient and Family)<sup>32</sup></li> <li>Open communication between patient/GP/carers<sup>32</sup></li> <li>Open communication about disease, management and prognosis<sup>32</sup></li> <li>GP and patients ambivalence to discuss poor prognosis</li> <li>Doctors to take initiative in discussing EOL issues<sup>24</sup></li> <li>HP taking time to listen/communicate<sup>32 33</sup></li> <li>Patients hesitant to see GP because they had tried to contact GP with unsatisfying results<sup>26</sup></li> </ul>
b. Inter-professional relationships between GP and other health professionals	<ul style="list-style-type: none"> <li>GP not familiar with treatments received by patients<sup>26</sup></li> <li>Patients hesitant to see GP because they perceived GP was not familiar enough with treatments given to patients<sup>26 27 31</sup></li> <li>GP needs to engage pro-actively with other health professionals<sup>26-28 31</sup></li> </ul>
3. Access and availability	<ul style="list-style-type: none"> <li>Time availability<sup>23 26-28 31</sup></li> <li>To GP, home visits<sup>23 24 27 30</sup></li> <li>Equity of access to all services irrespective of age<sup>30</sup></li> <li>Accessibility to GPs and other HPs<sup>23 24 30</sup></li> </ul>
4. GP clinical competence	<ul style="list-style-type: none"> <li>Expertise in management of symptoms<sup>23 32</sup></li> <li>Treating the disease/symptoms<sup>23 24 26</sup></li> <li>Communication with specialists, information sharing with specialists<sup>27 30</sup></li> <li>Sharing information with patient<sup>30</sup></li> </ul>
5. Multidisciplinary care	<ul style="list-style-type: none"> <li>Additional services/HPs to be involved<sup>28 30 31</sup></li> <li>Cooperation and working together, referrals<sup>27 29 32</sup></li> </ul>
6. A holistic approach	<ul style="list-style-type: none"> <li>Patients and GPs valued core factors in end-of-life care: availability of GP for home visits; clinical competence; continuity of care and collaboration with other HCPs<sup>23</sup></li> <li>Psycho-social-spiritual support are among most important attributes of EOL care<sup>30</sup></li> <li>Lack of awareness of type of support available from GP treatment and/or psychosocial support<sup>26</sup></li> </ul>

	<ul style="list-style-type: none"> <li>• Patient centred<sup>29 32</sup></li> <li>• ACP-anticipating various scenarios <sup>29</sup></li> <li>• GP legitimising the role of carer<sup>31</sup></li> <li>• GP supporting carers<sup>31</sup></li> <li>• GP understanding of physical/ psycho-social impact of caring<sup>25 31</sup></li> <li>• GP understanding available support for carers<sup>31</sup></li> <li>• Carer /family support to provide care for patient is important<sup>27</sup></li> <li>• Fostering 'completeness', advanced planning/preparation important attributes of EOL care <sup>33</sup></li> </ul>
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**Table 3.2: A description of the themes related to the advance care planning in primary care literature**

1. Uncertainty about the timing to begin ACP	<ul style="list-style-type: none"> <li>• ACP often happens too late <sup>41 51</sup> but patients want earlier <sup>45</sup></li> <li>• Often done ad hoc or when discharged from hospital <sup>41 46</sup></li> <li>• Disease trajectories for non-cancer patients makes identification to begin ACP difficult <sup>40-42</sup></li> <li>• More likely to be completed if in hospital rather than in community-recognition of changing clinical status <sup>46</sup></li> </ul>
2. Factors influencing GPs' completion of ACP	<ul style="list-style-type: none"> <li>• ACP not commonly done <sup>41 43 44 51</sup> <ul style="list-style-type: none"> <li>○ Age of GPs <sup>51</sup></li> <li>○ Attitude to ACP <sup>36 37 46 53</sup></li> <li>○ Clinical experience<sup>51</sup></li> <li>○ Comfort in discussing ACP <sup>42 51 52</sup></li> <li>○ Education and training in ACP <sup>36 37 40 45 46</sup></li> <li>○ Hospitalists better than GPs <sup>50</sup></li> <li>○ Involvement and training in palliative care <sup>52</sup></li> <li>○ Knowledge, skills and experience in ACP<sup>36 49 51 53</sup></li> <li>○ Lack of time <sup>39</sup></li> <li>○ Unclear roles <sup>45</sup></li> </ul> </li> <li>• ACP factors <ul style="list-style-type: none"> <li>○ Availability <sup>53</sup></li> <li>○ Currency <sup>53</sup></li> <li>○ Legal standing <sup>37 47</sup></li> <li>○ Standardisation of terminologies and systems <sup>36</sup></li> <li>○ Too many forms <sup>47</sup></li> </ul> </li> <li>• Validity of decisions <sup>46 47</sup></li> <li>• Facility / organisational factors <ul style="list-style-type: none"> <li>○ Including ACP discussions as standard care <sup>40</sup></li> <li>○ Protocols and systems esp in RACF <sup>38</sup></li> <li>○ Linking ACP to palliative care<sup>42 46</sup></li> <li>○ Care setting <sup>37 46</sup></li> </ul> </li> <li>• Certain conditions / diagnoses <ul style="list-style-type: none"> <li>○ Cancer [43]</li> <li>○ Dementia <sup>40</sup></li> <li>○ Heart failure [41]</li> <li>○ Non-cancer <sup>41 51</sup></li> </ul> </li> <li>• Patient factors <ul style="list-style-type: none"> <li>○ Lack of patient's awareness of diagnosis or prognosis<sup>40</sup></li> <li>○ Older patients <sup>42</sup></li> </ul> </li> <li>• Patient motivation and understanding of ACP<sup>40 45 53</sup></li> <li>• Concerns about ACP</li> <li>• Externally imposed system as driver<sup>46 47</sup> <ul style="list-style-type: none"> <li>○ Maintaining hope <sup>46</sup></li> </ul> </li> <li>• Patients able to make decisions in last 3 days</li> </ul>
3. Determinants of whether ACDs are implemented	<ul style="list-style-type: none"> <li>• ACP factors<sup>37 34, 43, 49]</sup></li> <li>• Timing of ACP <sup>41</sup></li> <li>• Patient illness factors<sup>37</sup></li> </ul>



	<ul style="list-style-type: none"> <li>• Organisation and care setting factors<sup>37</sup></li> <li>• Awareness<sup>37</sup></li> <li>• Attitudes of health professionals and family<sup>37</sup></li> </ul>
4. Outcomes of End of Life care if ACP in place	<ul style="list-style-type: none"> <li>• Regular contact/ visits by GPs in last week of life <sup>41 43</sup></li> <li>• Symptoms controlled<sup>50</sup></li> <li>• Patient satisfaction and improved care<sup>48</sup></li> </ul>

**Table 3.3: A description of the themes relating to the place of death literature**

1. Relationship between GP and nursing home visits and the likelihood of patients dying at home	<ul style="list-style-type: none"> <li>• Home visits conducted by GPs were strongly associated with the possibilities of a home death and place of preference<sup>56 63 66 67 72</sup></li> <li>• Home visit rate is a strong predictor of home death<sup>63 71</sup></li> <li>• Home visit rate by a GP is associated with lower frequency of emergency department visit in last weeks of life<sup>71</sup></li> <li>• GP home visit in last weeks of life impacts on place of death<sup>64</sup></li> <li>• Community nurse involvement increases the likelihood of a home death<sup>63 66</sup></li> </ul>
2. Relationship of the GPs awareness of preferred place of death, and the actual place of death	<ul style="list-style-type: none"> <li>• Patients and family members were the major source of a GPs knowledge of a patients preferred place of death<sup>62</sup></li> <li>• Most patients prefer to die at home<sup>56 62 65</sup></li> <li>• GP was more likely aware of patients preferred place of death if they were cared for at home, or receiving palliative care<sup>62</sup></li> <li>• GPs are often unaware of a patients preference for place of death<sup>56</sup></li> <li>• Patients are more likely to die at home or their preferred location if the patients preference is known by the GP<sup>56 59</sup></li> </ul>
3. Factors that influence a patient's preferred and actual place of death	<ul style="list-style-type: none"> <li>• Completion of an advance care plan or preferred place of care initiative with enhanced clinical care may increase the likelihood of a home death<sup>58 68</sup></li> <li>• GPs and community nurses who have an ongoing relationship with patients are more likely to facilitate discussions on preferred place of death<sup>70</sup></li> <li>• Being married and having children decreased likelihood of dying in hospital<sup>63</sup></li> <li>• Age is not associated with dying in preferred place<sup>61</sup></li> <li>• Preference for a home death weakens as death approaches, but still remains high<sup>65</sup></li> <li>• Longer time between diagnosis and death is associated with an out-of-hospital death<sup>63 72</sup></li> <li>• Ambiguous results as to whether living in urban setting increased the likelihood of a home death<sup>63 72</sup></li> <li>• Patients with severe dementia are more likely to die in care home or hospital compared to those with mild dementia<sup>60</sup></li> <li>• GPs and nurses prefer a patient dies at home or nursing home, but believe a hospital admission is justified if no better options exist<sup>58</sup></li> </ul>

**Table 3.4: A description of the themes related to the advance care planning in primary care literature**

5. Uncertainty about the timing to begin ACP	<ul style="list-style-type: none"> <li>• ACP often happens too late <sup>41 51</sup> but patients want earlier <sup>45</sup></li> <li>• Often done ad hoc or when discharged from hospital <sup>41 46</sup></li> <li>• Disease trajectories for non-cancer patients makes identification to begin ACP difficult <sup>40-42</sup></li> <li>• More likely to be completed if in hospital rather than in community-recognition of changing clinical status <sup>46</sup></li> </ul>
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6. Factors influencing GPs' completion of ACP	<ul style="list-style-type: none"> <li>• ACP not commonly done <sup>41 43 44 51</sup> <ul style="list-style-type: none"> <li>○ Age of GPs <sup>51</sup></li> <li>○ Attitude to ACP <sup>36 37 46 53</sup></li> <li>○ Clinical experience<sup>51</sup></li> <li>○ Comfort in discussing ACP <sup>42 51 52</sup></li> <li>○ Education and training in ACP <sup>36 37 40 45 46</sup></li> <li>○ Hospitalists better than GPs <sup>50</sup></li> <li>○ Involvement and training in palliative care <sup>52</sup></li> <li>○ Knowledge, skills and experience in ACP<sup>36 49 51 53</sup></li> <li>○ Lack of time <sup>39</sup></li> <li>○ Unclear roles <sup>45</sup></li> </ul> </li> <li>• ACP factors <ul style="list-style-type: none"> <li>○ Availability <sup>53</sup></li> <li>○ Currency <sup>53</sup></li> <li>○ Legal standing <sup>37 47</sup></li> <li>○ Standardisation of terminologies and systems <sup>36</sup></li> <li>○ Too many forms <sup>47</sup></li> </ul> </li> <li>• Validity of decisions <sup>46 47</sup></li> <li>• Facility / organisational factors <ul style="list-style-type: none"> <li>○ Including ACP discussions as standard care <sup>40</sup></li> <li>○ Protocols and systems esp in RACF <sup>38</sup></li> <li>○ Linking ACP to palliative care<sup>42 46</sup></li> <li>○ Care setting <sup>37 46</sup></li> </ul> </li> <li>• Certain conditions / diagnoses <ul style="list-style-type: none"> <li>○ Cancer [43]</li> <li>○ Dementia <sup>40</sup></li> <li>○ Heart failure [41]</li> <li>○ Non-cancer <sup>41 51</sup></li> </ul> </li> <li>• Patient factors <ul style="list-style-type: none"> <li>○ Lack of patient's awareness of diagnosis or prognosis<sup>40</sup></li> <li>○ Older patients <sup>42</sup></li> </ul> </li> <li>• Patient motivation and understanding of ACP<sup>40 45 53</sup></li> <li>• Concerns about ACP</li> <li>• Externally imposed system as driver<sup>46 47</sup> <ul style="list-style-type: none"> <li>○ Maintaining hope <sup>46</sup></li> </ul> </li> <li>• Patients able to make decisions in last 3 days</li> </ul>
7. Determinants of whether ACDs are implemented	<ul style="list-style-type: none"> <li>• ACP factors<sup>37 34, 43, 49]</sup></li> <li>• Timing of ACP <sup>41</sup></li> <li>• Patient illness factors<sup>37</sup></li> <li>• Organisation and care setting factors<sup>37</sup></li> <li>• Awareness<sup>37</sup></li> <li>• Attitudes of health professionals and family<sup>37</sup></li> </ul>
8. Outcomes of End of Life care if ACP in place	<ul style="list-style-type: none"> <li>• Regular contact/ visits by GPs in last week of life <sup>41 43</sup></li> <li>• Symptoms controlled<sup>50</sup></li> <li>• Patient satisfaction and improved care<sup>48</sup></li> </ul>

**Table 3.5: A description of the themes relating to the place of death literature**

4. Relationship between GP and nursing home visits and the likelihood of patients dying at home	<ul style="list-style-type: none"> <li>• Home visits conducted by GPs were strongly associated with the possibilities of a home death and place of preference<sup>56 63 66 67 72</sup></li> <li>• Home visit rate is a strong predictor of home death<sup>63 71</sup></li> <li>• Home visit rate by a GP is associated with lower frequency of emergency department visit in last weeks of life<sup>71</sup></li> <li>• GP home visit in lasts weeks of life impacts on place of death<sup>64</sup></li> <li>• Community nurse involvement increases the likelihood of a home death<sup>63 66</sup></li> </ul>
5. Relationship of the GPs awareness of	<ul style="list-style-type: none"> <li>• Patients and family members were the major source of a GPs knowledge of a patients preferred place of death<sup>62</sup></li> </ul>

preferred place of death, and the actual place of death	<ul style="list-style-type: none"> <li>• Most patients prefer to die at home<sup>56 62 65</sup></li> <li>• GP was more likely aware of patients preferred place of death if they were cared for at home, or receiving palliative care<sup>62</sup></li> <li>• GPs are often unaware of a patients preference for place of death<sup>56</sup></li> <li>• Patients are more likely to die at home or their preferred location if the patients preference is known by the GP<sup>56 59</sup></li> </ul>
6. Factors that influence a patient's preferred and actual place of death	<ul style="list-style-type: none"> <li>• Completion of an advance care plan or preferred place of care initiative with enhanced clinical care may increase the likelihood of a home death<sup>58 68</sup></li> <li>• GPs and community nurses who have an ongoing relationship with patients are more likely to facilitate discussions on preferred place of death<sup>70</sup></li> <li>• Being married and having children decreased likelihood of dying in hospital<sup>63</sup></li> <li>• Age is not associated with dying in preferred place<sup>61</sup></li> <li>• Preference for a home death weakens as death approaches, but still remains high<sup>65</sup></li> <li>• Longer time between diagnosis and death is associated with an out-of-hospital death<sup>63 72</sup></li> <li>• Ambiguous results as to whether living in urban setting increased the likelihood of a home death<sup>63 72</sup></li> <li>• Patients with severe dementia are more likely to die in care home or hospital compared to those with mild dementia<sup>60</sup></li> <li>• GPs and nurses prefer a patient dies at home or nursing home, but believe a hospital admission is justified if no better options exist<sup>58</sup></li> </ul>